

THE EXPERIENCES OF AFRICAN ELDERLY WOMEN AS CAREGIVERS OF THEIR ADULT CHILDREN WITH AIDS RELATED ILLNESS

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Abstract

Background: In South Africa, AIDS patients are increasingly cared for at home by women in their traditional role of family caregiver. The number of parents assuming care for their adult children infected with HIV and with AIDS related illness is increasing and this affects parents negatively. The purpose of this phenomenological qualitative study was to capture the lived experiences of African elderly women as caregivers in the challenging context of family members who are receiving antiretroviral therapy.

Methods: Using Van Manen's method for hermeneutical phenomenological research, the lived experiences of 10 African elderly women who were the primary caregivers for their HIV-positive adult children were investigated. In-depth interviews were employed as the method of data collection and in order to facilitate this process, an interview guide was developed. Transcription and analysis of the interviews began immediately following the first interview and was preceded by analyzing the transcribed interviews, line by line, highlighting important ideas and themes. Each theme was coded and recoded using Ethnographic computer program

Results: Carers struggled with the physical impact of this disease; there was a clear nexus between the carer's coping capacity and the PLWHA's physical health. As the PLWHA's health declined carers' coping skills were put to the test and new boundaries set. While carers were often 'forced' into silence by the PLWHA, there was a demonstrated desire throughout the research process for these carers to 'debrief' and discuss their past or current care. Of the caregiving, personal care was most difficult and household tasks were most time consuming. Family life, with friends was areas most likely to be affected by caregiving.

Conclusions: While it may seem that the carers are coping with care of their children with AIDS, the outer façade is not always an accurate portrayal of the true situation. Health care workers should enquire as to the assistance these carers need from the social and health care services in order to continue to care for their children having AIDS related illness.

Keywords: Family; caregiver; person living with HIV/AIDS; experiences, Gugulethu.

Background to investigation

AIDS is no longer a death sentence. Current health challenges related to HIV/AIDS have changed markedly since the use of the newer medications called protease inhibitors. The combination of the newer and older drugs used to treat HIV called highly active antiretroviral therapy (HAART), has changed HIV/AIDS from a fatal illness to a chronic, but manageable condition (Thompson, 2004). According to Pujol (2006), at the end of 1995, there were only six antiretroviral medications; however, by the close of 2005, there were 28 HIV medications. Consequent to these medications entering the picture around 1996, the estimated number of deaths in the first two quarters of 1996

was 12 percent less than the estimated number of deaths during the first two quarters of 1995 (Wheeler & Shernoff, 1999). Thus, since 1996, HIV/AIDS changed from a terminal illness to a chronic and potentially manageable one. The caregiver role has changed also as physical and emotional preparation for the death of a loved one are no longer routine. Today, the focus and overall experience of informal caregiving have shifted, and there is a dearth of contemporary research on the experience and rewards of informal caregiving. This study examined the experience, including challenges, and rewards of informal caregiving specific to African elderly women caring for their adult children with AIDS.

Methods

Hermeneutic phenomenology is an appropriate method for this research, enabling the phenomena of life's experience to be structurally and systematically analysed, thereby allowing in-depth interpretation of these lived experiences. The purpose of this form of research '...is to act as an advocate in progressing human life, by increasing its thoughtfulness and sensitivity to situations' (van Manen, 1990, p. 21). The study adopted a qualitative research approach. Within this approach a phenomenological orientation was accepted since the objectives were to explore subjective meanings and experiences from the respondent's points of view.

Setting and participants

The sample was homogenous in that all the participants were African Xhosa-speaking elderly women who were taking care of a person living with HIV/AIDS and living in Gugulethu Township. The elderly women were from similar socio-cultural contexts. Participants were caregivers at the time of the study and had relatives that have been patients at Gugulethu HIV/AIDS Clinic at some stage during their HIV illness. All participants were above the age of 57 years, had been involved in taking care of a relative living with HIV/AIDS and had shared the same household with their loved one throughout the care giving experience. Five participants had relocated from their permanent place of residence to engage in care giving. All caregivers had anticipated and desired that their loved one die at home.

A non-probability sampling technique was applied to gain a purposive sample. Ten respondents from Gugulethu ARV Clinic were selected from information obtained on antiretroviral (ARV) register in Gugulethu ARV Hannan treatment Centre. These individuals were identified for their potential to elicit valuable information regarding the effects of HIV/AIDS according to four criteria:

- Taking care of a person living with HIV/AIDS
- Above the age of 57 years
- African elderly women living in Gugulethu Township at time of the study
- Women from the age of 57 who were willing to be interviewed by the researcher about the phenomenon and participate in a follow-up interview.

Data collection

Data was collected by structured, in-depth, face-to-face interviews. Interviews lasted from 45-90 minutes. Observational field notes (Lincoln and Guba, 1985; Boyd, 1993) and theoretical memos and diagrams (Strauss and Corbin, 1990) were also used during data collection to ensure a more accurate and thorough recollection of the circumstances surrounding the interview and participants' experience. Interviews were conducted at the site of the Church where the support group was conducted. The researcher conducted all interviews personally, which enabled him to change the wording of questions while maintaining the intended meaning of the question in those instances where participants did not understand the original wording. The researcher taped the interviews after seeking consent from the participants (when permission was granted) and also took written field notes to maximise the accuracy of the recording of the responses. Two interviews were conducted to verify the first views of the participants.

Data analysis

To analyse the data generated by the in-depth interviews, the data were audio-taped, transcribed, and subjected to qualitative data analysis. Transcription and analysis of the interviews began immediately following the first interview and was preceded by analyzing the transcribed interviews, line by line, highlighting important ideas and themes. Each theme was coded and recoded using and Ethnographic computer program (Siegel, Lune, & Meyer, 1998). Codes were then grouped together and sorted into categories. To ensure credibility of the data, follow-up interviews were conducted with the ten participants, and all participants were sent a summary of the analysis. Participants were asked to comment on the truth of the descriptions and impressions derived from the interviews in order to verify the validity of the data analysis.

Ethical consideration

A study of people affected and infected with HIV/AIDS needs to be approached with great sensitivity. The stigma of HIV is such that HIV positive interviewees may fear discrimination, rejection or even violence if their HIV status is revealed. Research on HIV explores the most intimate sphere of a person's private, sexual and

emotional life. An interview can become a difficult and emotional experience, regardless of how well a person seems to be coping. Morse and Richards (2002: 205) identify the following ethical principles regarding participants' rights:

- The right to be informed of the purpose of the study as well as what is expected during the research process. The amount of participation and time required. What information will be obtained and who will have access to it. Finally what the information will be used for.
- The right to confidentiality and anonymity.
- The right to ask questions of the researcher.
- The right to refuse to answer questions the researcher may ask, without negative ramifications.
- The right to withdraw from the study at any time without negative ramifications.

Results (All names are pseudonyms)

Caregiving is overwhelming

Caregivers described the work of HIV/AIDS caregiving as overwhelming and time consuming. Caring for the ill person with HIV/AIDS becomes overwhelming when a PLWA is seriously ill and experiences the deterioration of physical and mental health, and the work load for the caregivers increases. About half of the caregivers indicated that they felt overwhelmed when they were providing care for their beloved family members. Some examples of the caregivers' experiences that produced feelings of being overwhelmed are presented:

A 67-year-old female caregiver (Mrs Nathi's story) who cared for her older son (Puleng; 45 years old) explained:

"I took care of his activities of daily living such as eating, bathing, and eliminating. He had diarrhoea 10 times each day. No one helped me when he was dependent and needed care. I had one sister, but she worked outside. I am too old to help him take care of himself and I have my own severe illnesses, too. I spent all of my time trying to take care of him. Sometimes I felt so tired and I could not sleep well. During that time, I tell you the truth..., I felt fatigue and like I was suffering." (Case #1).

Caregiving Difficulties

During the course of care, some caregivers described their experiences of caregiving difficulties

when they had to deal with emotional changes of PLWAs, and manage the severe symptoms of PLWAs, and attend to other household jobs as well. Two caregivers stated that they could not manage the situations when the PLWAs had emotional distress and they worried about whom they could ask for help if needed.

A 57 year-old female caregiver (Mrs Bonke's story) who cared for her daughter (34 years old) had this to say.

"She used to be a talkative and easy going person. She had lots of friends. But now (after she was diagnosed with the disease and became symptomatic), she changed her personality and separated herself from others. She did not want to contact her friends. When her friends called, she refused to talk to them. I felt worried about her; she used to say that she wanted to die. It was hard for me to take care of her." (Case #7)

Seeking Knowledge about HIV/AIDS

All caregivers had learned about the nature of HIV/AIDS and factors affecting health and the disease progression of PLWAs. They utilized several methods to learn about the disease. A 60 year-old female caregiver (Mrs Wongani's story who was HIV positive) who cared for her son, Wanini (32 years old) sought knowledge in the following manner.

"At first, I did not know about the AIDS disease. I did not pay attention to it because I thought I would not be close to the disease. Then, I was frightened when I learned that my son was HIV positive. Finally, I also learned that I was HIV positive... Now, I think a lot. I had to search for more information about the disease to get to know how it affected a person's health. Now I know, if I take good care of myself, I can live longer. Right now, I am fine, my health is okay. I took care of my son during the time he stayed at home." (Case #4)

When caregivers learned that they had to take care of their loved ones with HIV/AIDS, they needed to know about the disease so that they could provide proper care for the ill family members, and how to take good care of themselves. A 65-year-old female caregiver (Mrs Moni's story) who cared for her 2nd son (26 years old) made this observation.

"I searched for information about HIV/AIDS disease from books, magazines, and from health care providers. Who never told me that I could find good medicines such as herbs and vitamins; I would go and buy them. Then I would give the medicines to my son with the hope that he would get well soon." (Case #5)

Encouraging the PLWAs to be Strong and Positive in Mind

Kinser (2002) stated that positive attitudes and emotions could affect the biochemistry of the body and help to enable the personal healing process by increasing the person's capacity to manage the illness, improving their physical condition, and helping them to achieve a sense of well-being. When assisting PLWAs, it is important to alleviate negative experiences, and prevent situations and events that could trigger the sense of despair and hopelessness. In general, despair and hopelessness are associated with suffering (Kylmä, Vehviläinen-Julkunen, & Lähdevirta, 2000; Lindholm & Eriksson, 1993). On the other hand, hope helps with healing and provides the sick person with a positive outlook on the future. Six of the 10 caregivers specifically mentioned that their loved ones wanted emotional and spiritual support with the positive message of hope. The caregivers' thoughts about emotional and spiritual support are illuminated.

A 67 year-old female caregiver (Nathi's story) who cared for her older son (45 years old) shared these thoughts.

"I gave him supportive words. For example, I said, do not think about the disease too much because it makes you feel stress and stress is not good for your health." (Case #1) *"I encouraged him to pray in order to keep his mind calm and to distract his thoughts from the illness."* (Case #1)

A 64-year-old female caregiver (Mrs Phethani's story) who cared for his youngest daughter (25 years old) also shared her thoughts.

"During the time her condition was deteriorating, I thought that emotional support was essential for her. It was my business to cheer my daughter up. I stayed with her; I served her good nutrition and vitamins. I advised her to just relax and do not become

discouraged. All of these things are helpful for her health and her improvement. I was happy when I saw her health was better." (Case #3)

Personal Care: Helping with Activities of Daily Living

Caregivers shared descriptions of the personal care that they provided: activities of daily living included assistance with eating, bathing, and toileting.

A 67 year-old female caregiver (Mrs Nathi's story) who cared for her older son (45 years old) shared these sentiments with the researcher.

"I cooked for everyone in my family. We ate together and that included Puleng, my son with the disease. My son had low immunity and was susceptible to opportunistic infections. The food must be fresh and clean... I was afraid that he might not receive enough nutrition, so I gave him supplemental food products such as chocolate milk or soy milk." (Case #1)

"When his health was getting worse, he could not go to the toilet himself, and I served him with a bedpan. Then I had to clean him up after he defecated." (Case #5, Mon's story)

Medical Care

This category included a variety of caregiving activities, such as preparing medications, and managing follow-up treatments and appointments. Caregivers dispensed medications according to the physicians' prescriptions.

"The medicine that the physician prescribed for him when he had fever well; I gave it to him when he needed it." (Case #2, Mrs Lulama's story) *"I reminded her to take her medicine on time because sometimes she forgot."* (Case #3, Mrs Phethani's story)

Caregivers helped with arrangements for follow-up treatments when their loved ones had abnormal signs and symptoms such as fever, headache, diarrhoea, nausea, and vomiting.

"His health was very bad. I was worried about him. When I observed his abnormal signs, I did not hesitate to bring him to see the doctor." (Case #1, Mrs Nathi's story)

In addition, some PLWAs required medical interventions such as tube feeding and wound

dressing. Caregivers said that they provided those treatments and learned to do them correctly. They also had to learn about managing abnormal signs and symptoms.

A 65 year-old female caregiver (Mrs Nozizwe' story) who cared for her daughter (28 years old) explained how she managed the interventions.

"My daughter was very sick. She could not eat by herself. The physician inserted the nasogastric tube in her stomach. I learned how to blend food and how to feed my daughter. I also monitored the amount of food she ate. During some meals I had to add more food this happened when I observed that she could eat more." (Case #9)

A 67-year-old female caregiver (Mrs Nathi's story) who cared for her older son (45 years old) monitored him closely and with care.

"He had a mouth ulcer and white plaque on the tongue. He felt pain when he would try to eat. So I cooked soft diets such as noodles, soup, or boiled rice for him." (Case #1) *"He passed runny stools about 10 times a day. I served him a bed pan and cleaned his body after elimination. Later, I bought pampers and used them. They were easier to use, but more expensive. His bodily discharges were kept separately from other items, placed in a plastic bag, and put in the garbage."* (Case #1)

Tender loving care.

Tender loving care was evident among the caregivers in this study. All caregivers tried to provide their family members with love and support. They helped their ill family members through showing them compassion; they also tried to find the beneficial ways to alleviate their loved ones' suffering.

"The first time I knew that both of us were HIV positive, I was frightened. I thought that was impossible. But we did not make an argument out of this situation. We tried to give support to each other. Even though we knew that there was no cure, we could live longer if we could provide good self care for ourselves, and be careful with our health habits. Above of all, I loved my son very much." (Case #4, Mrs Wongani's story)

Helping the PLWAs to relax and enabling the practice of religious beliefs.

Caregivers helped PLWAs to relax and allowed them to participate in activities as usual, when possible. Activities such as watching television, exercising, praying, and meditations were some of the activities that seemed to help the ill family members.

A 67 year-old female caregiver (Mrs Nathi's story) who cared for her older son (45 years old) participated in some activities that she thought helped her son.

"I and my son went to the church to listen to the word of God because we believed that the word of God would help my son to relax and feel calm. This relaxation might help to strengthen his immune system. At night, I encouraged my son to pray in order to keep his mind calm." (Case #1)

In conclusion, caregivers of PLWAs provided assistance to their ill family members. They helped with personal care, including aiding them with eating, bathing, and eliminating activities. They also managed their ill family members' medical care and interventions. Moreover, caregivers engaged in providing emotional and spiritual support to their loved ones in order to help them remain hopeful and strong.

Discussion

Suffering has been referred to as a human state of anguish because of bearing pain, injury, or loss (Copp, 1974). Suffering also refers to the negative experience in caregiving or any threat to personal integrity (Poulshock & Deimling, 1984). The word suffering in African philosophy is related to sickness, negative feelings, and the association with what is unpleasant (Sutthiyano, 1999). In this study, caregivers experienced suffering when they felt overwhelmed and difficulties in caring for PLWAs. Caregivers described the tasks and responsibilities of a caregiver as overwhelming and difficult. This finding was consistent with earlier studies that indicated that the demands of caregiving of PLWAs were overwhelming (Brown et al., 1995; Phengjard et al., 2002; Kipp et al., 2007). The demands of caregiving for PLWAs increase as the disease progresses (Pearlin et al., 1997). In studying family caregiving experiences of providing

care at home for dying loved ones with HIV/AIDS, Stajduhar (1998, p. 17) found that caregivers described their work of HIV/AIDS caregiving as a "cycle", "responsibility", "overwhelming", "ongoing", and "never ending."

Consistent with similar international studies, Kipp and colleagues (2006a) found that almost all caregivers of spouses with HIV/AIDS in Bumbu, Kinshasa, Democratic Republic of Congo reported that providing care for PLWAs was difficult and stressful. In addition, Casida (2005) and Luttik and colleagues (2007) found that caregivers had to perform caregiving tasks, which were associated with feelings of burdens and being overwhelmed, particularly when the tasks involved personal care and activities of daily living.

However, the participants also offered a supportive role, in the form of seeking knowledge about HIV/AIDS and encouraging the PLWAs to be strong and positive in mind. This is similar to the study by Stetz and Brown (1997), who reported that one strategy for taking care of persons with cancer and AIDS emerged was seeking and obtaining information. These strategies involved finding information about the disease and referral resources. These caregivers and the ill persons needed to understand the disease in order for the caregivers to provide better care for the ill persons (Stetz & Brown, 1997). This current research revealed that although the caregivers faced the uncertainty of the disease progression and the impending death of the PLWAs that could take place at any time, they still maintained hope. They did not ignore the PLWAs' needs and they gave them supportive words of encouragement. For example, they offered sufficient food and medications with the hope that the PLWAs would recover or attain better health. This finding was consistent with the previous reports about PLWAs caregivers. Baker (2003), Kespichayatana and VanLandingham (2003), McCann and Wadsworth (1992), Saengtienchai and Knodel (2001), and Wardlaw (1994) reported that the majority of caregivers provided emotional support and comfort to the PLWAs.

Conclusion

The area of HIV/AIDS provides a challenge to address both the physical and sociological aspects

of clients and other individuals important to the client. This research has focused upon carers. I chose this area as carers' voices are often not heard by health-care professionals. While the findings clearly explored the lived experiences of the carers who took part, health care professionals need to be aware there are other people, not just the ill client who are affected by HIV/AIDS. This article highlights the carers' daily struggle to provide help and assistance to their loved ones living with HIV/AIDS, thus giving insights to health care professionals about what assistance they could offer carers to assist ill clients.

Exploring how these carers cared for someone living with HIV/AIDS also highlighted their relationships with their communities. This is an area neglected by many researchers because many researchers choose to focus upon the pathology of HIV/AIDS. There has been an overall lack of focus upon the sociological effects of this illness on the caregiver. The research identified compassionate, intimate and caring relationships that were challenged by HIV/AIDS, yet the elderly women made a conscious decision to care for their infected adult children. This conscious decision often meant the carer witnessed the decline of their children's health, often to eventual death.

Implications for research

This study illustrates the need for further research into the development and implementation of support programmes for the caregivers, as well as further research regarding the reduction of stigma surrounding HIV/AIDS.

References

- Andelowski, M. (1986). The problem of rigor in qualitative research. *Advance Nursing Science*, 8(3), 27-37.
- Aoun, S. M., Kristjanson, L. J., Currow, D., & Hudson, P. (2005). Caregiving for the terminally ill: At what cost? *Palliative Medicine*, 19, 551-555.
- Baker, S. (2003). African American caregivers and HIV/AIDS formal resources. *The ABNF Journal*, 14(2), 36-40.
- Boyd, C. O. (1993). Toward a nursing practice research method. *Advances in Nursing Science* 16(2), 9-25.
- Brown, A. E., McDaniel, J. L., & Birx, E. C. (1995). Stressors, needs, and resources: What AIDS home caregivers have to say. *Caring*, 14(4), 60-61, 63-64.
- Buehler, J. A., & Lee, H. J. (1992). Exploration of home

- care resources for rural families with cancer. *Cancer Nursing*, 15, 299-308.
- Casida, J. (2005). The lived experience of spouses of patients with a left ventricular assist device before heart transplantation. *American Journal of Critical Care*, 14, 145-151.
- Cherlin, A. (1983). Changing family and household: Contemporary lessons from historical research. *Annual Review of Sociology*, 9, 51-66.
- Copp, L. A. (1974). The spectrum of suffering. *American Journal of Nursing*, 74, 491-494.
- Colaizzi, P. F. (1973). Reflection and research in psychology: A phenomenological study of learning. Kendal/Hunt Publishing Co.
- D'Avanzo, C., Frye, B., & Froman, R. (1994). Stress in Cambodian refugee families. *IMAGE: Journal of Nursing Scholarship*, 26, 101-105.
- Department of Health. (2006). National HIV and syphilis antenatal seroprevalence survey in South Africa, 2002. Summary report. Pretoria: Department of Health.
- Department of Health. (2008). Guidelines for the community home based care. Government Press, Pretoria.
- Farran, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. S. (1991). Findings meaning: An alternative paradigm for Alzheimer's disease family caregivers. *The Gerontologist*, 31, 483-489.
- Flaskerud, J. H., & Lee, P. (2001). Vulnerability to health problems of female informal caregivers of HIV/AIDS and age-related dementias. *Journal of Advanced Nursing*, 33, 60-68.
- Giorgi, A. (2005). The phenomenological movement and research in the human sciences. *Nursing Science Quarterly*, 18(1), 75-82.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice Hall.
- Hoening, H. G. (2002). 83-years old women with chronic illness and strong religious beliefs. *Journal of the American Medical Association*, 288, 487-493.
- Hycner, M. A. (1985). A philosophical method to study nursing phenomena. In M. Leininger (Ed.). *Qualitative research methods in nursing. New readings in cultural anthropology*. Harper Collins Publisher. New York.
- Jones, S., Roth, D., & Jones, P. K. (2002). Effects of demographic and behavioural variables on burden of caregivers of chronic mentally ill persons. *Psychiatric Services*, 46, 141-145.
- Jorgensen, M. J., & Marwit, S. J. (2001). Emotional support needs of gay males with AIDS. *AIDS Care*, 13, 171-175.
- Katapa, R. S. (2004). Caretakers of AIDS patients in rural Tanzania. *International of STD & AIDS*, 15, 673-678.
- Keene, M. (2007). *Buddhist beliefs and issues*. New York: Badger.
- Kespichayawattana, J., & VanLandingham, M. (2003). Effects of coresidence and caregiving on health of Thai parents of adult children with AIDS. *Journal of Nursing Scholarship*, 35, 217-224.
- Kinser, P. (2002). *Psychoneuroimmunology and Natural Healing by the Brain*. Retrieve August 22, 2008, from <http://serendip.brynmawr.edu/bb/neuro/neuro99/web2/Kinser.html>
- Kipp, W., Matukala Nkosi, T., Laing, L., & Jhangri, G. S. (2006a). Care burden and self reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo. *AIDS Care*, 18, 694-697.
- Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E., & Bajenja, E. (2007). Family caregivers in rural Uganda: The hidden reality. *Health Care for Women International*, 28, 856-871.
- Knodel, J., & Im-Em, W. (2004). The economic consequences for parents of losing an Adult child to AIDS: Evidence from Thailand. *Social Science & Medicine*, 59, 987-1001.
- Kylmä, J., Vehviläinen-Julkunen, K., & Lähdevirta, J. (2000). Hope, despair and hopelessness in living with HIV/AIDS: A grounded theory study. *Journal of Advanced Nursing*, 33, 764-775.
- Limpanichkul Y., & Magilvy, K. (2004). Managing caregiving at home: Thai caregivers living in the United States. *Journal of Cultural Diversity*, 11, 18-24.
- Lindholm, L., & Eriksson, K. (1993). To understand and alleviate suffering in a caring culture. *Journal of Advanced Nursing*, 18, 1354-1361.
- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*. New York: Sage.
- London, A. S., Fleishman, J. A., Goldman, D. P., McCaffrey, D. F., Bozzette, S. A., Shapiro, M. F., et al. (2001). Use of unpaid and paid home care services among people with HIV infection in the USA. *AIDS Care*, 13(1), 99-121.
- Luttik, M. L., Jaarsma, T., Veeger, N., Tijssen, J., Sanderman, R., & van Veldhuisen, D. J. (2007). Caregiver burden in partners of heart failure patients: Limited influence of disease severity. *European Journal of Heart Failure*, 9, 695-701.
- Mackenzie, A., Perry, L., Lockhart, E., Cottee, M., Cloud, G., & Mann, H. (2007). Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. *Disability and Rehabilitation*, 29(2), 111-121.

- May, J. (1998). *Experience and Perceptions of Poverty in South Africa*. Durban: Glenwood Publishing.
- McCann, K., & Wadsworth, E. (1992). The role of informal carers in supporting gay men who have HIV related illness: What do they do and what are their needs? *AIDS Care*, 4, 25-34.
- McIlfatrick, S., Sullivan, K., & McKenna, H. (2006). What about the carers? Exploring the experience of caregivers in a chemotherapy day hospital setting. *European Journal of Oncology Nursing*, 10, 294-303.
- Mintz, S. (1995). Family caregivers. *Caring Magazine*, 7(3), 7-10.
- Morse, J.M., & Richard, L. (2002). *Read me first for a user's guide to qualitative methods*. London: Sage.
- Mui, A. C. (1992). Caregiver strain among black and white daughter caregivers: A role theory perspective. *The Gerontologist*, 32, 203-212.
- Nkongho, N. O., & Archbold, P. G. (1995). Reasons for caregiving in African American families. *Journal of Cultural Diversity*, 2, 116-123.
- Nokes, K. M., Kendrew, J., & Longo, M. (1995). Alternative/complementary therapies used by persons with HIV disease. *Journal of the Association of Nurses in AIDS Care*, 6, 19-24.
- Nyamathi, A., Covington, C., & Mutere, M. (2007). Vulnerable populations in Thailand: Giving voice to women living with HIV/AIDS. *Annual Review of Nursing Research*, 25, 339-355.
- Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18, 236-240.
- Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers. *The Gerontologist*, 39, 177-185.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage Publications.
- Pearlin, L. I., Aneshensel, C. S., & LeBlanc, A. J. (1997). The forms and mechanisms of stress proliferation: The case of AIDS caregivers. *Journal of Health and Social Behavior*, 38, 223-236.
- Pederson, A., & Greaves, L. (2006). Gender and the costs of palliative caregiving for people with HIV/AIDS. *Research Bulletin of the Centers of Excellence for Women's Health*. 5(2), 18-19.
- Phengjard, J., Brown, M. A., Swansen, K. M., & Schepp, K. G. (2002). Family Caregiving of persons living with HIV/AIDS (PLWAs) in urban Thailand. *Thai Journal of Nursing Research*, 6(3), 87-100.
- Pinquart, M., & Sörenson, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and aging*, 18, 250- 267.
- Poulshock, S. W., & Deimling, G. T. (1984). Families caring for elders in residence: Issues in the measurement of burden. *Journal of Gerontology*, 39, 230-239.
- Pujol, G. (2006, January/February). HAART turns 10. *The Body: The Complete HIV/AIDS Resource*. Retrieved October 29, 2006 from, <http://www.thebody.co/aspjanfeb06/haart10.html>
- Rotheram-Borus, M. J., Flannery, D., Rice, E., & Lester, P. (2005). Families living with HIV. *AIDS Care*, 17, 978-987.
- Rungreangkulkij, S., & Chesla, C. (2001). Smooth a heart with water: Thai mothers care for a child with schizophrenia. *Archives of Psychiatric Nursing*, 15(3), 120-127.
- Saengtienchai, C., & Knodel, J. (2001). *Parents providing care to adult sons and daughters with HIV/AIDS in Thailand*. Geneva, Switzerland: UNAIDS.
- Sawatzky, J. E., & Fowler-Kerry, S. (2003). Impact of caregiving: Listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing*, 10, 277-286.
- Sethabouppha, H., & Kane, C. (2005). Caring for the seriously mentally ill in Thailand: Buddhist family caregiving. *Archives of Psychiatric Nursing*, 19(2), 44-57.
- Shahabi, L., Powell, L. H., Musick, M. A., Pargament, K. I., Thoresen, C. E., Williams, D., et al. (2002). Correlates of self-perceptions of spirituality in American adults. *Annals of Behavioral Medicine*, 24, 59-68.
- Sherman, D. W., Ye, X. Y., McSherry, C., Calabrese, M., Parkas, V., & Gatto, M. (2005). Spiritual well-being as a dimension of quality of life for patients with advanced cancer and AIDS and their family caregivers: Results of a longitudinal study. *The American Journal of Hospice & Palliative care*, 22, 349-362.
- Siriopoulao, G., Brown, Y., & Wright, K. (1999). Caregivers of wives diagnosed with Alzheimer's disease: Husbands' perspectives. *American Journal of Alzheimer's Disease*, 14(2), 79-87.
- Songwathana, P. (2001). Women and AIDS caregiving: Women's work? *Health Care for Women International*, 22, 263-279.
- Stajduhar, K. I., & Davies, B. (1998). Palliative care at home: Reflections on HIV/AIDS family caregiving experiences. *Journal of Palliative Care*, 14(2), 14-22.

- Stetz, K. M., & Brown, M. A. (1997). Taking care: Caregiving to persons with cancer and AIDS. *Cancer Nursing*, 20, 12-22.
- Strauss and Corbin (1990). *Basics of qualitative research: techniques and procedures for developing grounded theory*. Cambridge, England: Cambridge University Press.
- Subgranon, R., & Lund, D. (2000). Maintaining Caregiving at Home: A Culturally Sensitive Grounded Theory of Providing Care in Thailand. *Journal of Transcultural Nursing*, 11, 166-173.
- Sutthiyano, P. (1999). Buddhist philosophy: Lecture note for nursing doctoral students. Chiang Mai: Chiang Mai University.
- Thompson, D. (2004). Positive Aspects of Caregiving: Contributions of the REACH Project to the Development of New Measures for Alzheimer's Caregiving. *Research on Aging*, 26, 429-453.
- Turner, H. A., & Catania, J. A. (1997). Informal caregiving to persons with AIDS in the United States: Caregiver burden among central cities residents eighteen to forty nine years old. *American Journal of Community Psychology*, 25, 35-59.
- Turner, H. A., Catania, J. A., & Gagnon, J. (1994). The prevalence of informal caregiving to persons with AIDS in the United States: Caregiver characteristics and their implications. *Social Science & Medicine*, 38, 1543-1552.
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Thousand Oaks, Canada: The Althouse Press.
- Van de Ven, P., Kippax, S., Crawford, J., French, J., Prestage, G., Grulich, A., Kaldor, J. & Kinder, P. (1997). Sexual practices in a broad cross-sectional sample of Sydney gay men. *Australian and New Zealand Journal of Public Health*, 21(7), 762-766.
- Wacharasin, C., & Homchampa, P. (2008). Uncovering a family caregiving model: Insights from research to benefit HIV-infected patients, their caregivers, and health professionals. *Journal of the Association of Nurses in AIDS Care*, 9, 385- 396.
- Wardlaw, L. A. (1994). Sustaining informal caregivers for persons with AIDS. *Families in Society*, 75, 373-384.
- Wheeler, D. P., & Shernoff, M. (1999). The role of mental health professionals in medical decision making regarding protease inhibitors. In M. Shernoff (Ed.), *AIDS and mental health practice: Clinical and policy issues* (pp. 3-18). New York: The Haworth Press.
- Wight, R. G., LeBlanc, A. J., & Aneshensel, C. S. (1998). AIDS caregiving and health among midlife and older women. *Health Psychology*, 17, 130-137.
- Wood, J. B., & Parham, I. A. (1990). Coping with perceived burden: Ethnic and cultural issues in Alzheimer's family caregiving. *Journal of Applied Gerontology*, 9, 325-339.